DOCUMENT RESUME

ED 193 822 EC 130 142

AUTHOR Smith, Carl R., Ed.
TITLE Iowa Perspective, Vol. 5, No. 4.
INSTITUTION Iowa State Dept. of Public Instruction, Des Moines. Div. of Special Education.
PUB DATE May 80
NOTE 12p.
JOURNAL CIT Iowa Perspective; v5 n4 May 1980

EDRS PRICE MF01/PC01 Plus Postage.
DESCRIPTORS *Autism; Cost Effectiveness; *Definitions; *Identification; Opinions; Policy; *State Legislation; *Student Placement; *Therapy
IDENTIFIERS *Iowa

ABSTRACT

The issue presents four articles on autism. The first, "Current Issues in Programming for Autistic Children and Young Adults" by Bruce Balow, examines six issues which touch upon such aspects as definitions, identification, placement, treatment style, programs needed, cost effectiveness, and influence on policy and politics. The second article, "A Parent Responds" by Nicole Raaz, presents the response of a parent of an autistic child to the first article. Each issue of Balow's article is examined critically. The third article, "An Iowa Professional Responds" by Polly Arp, presents the response of a supervisor of emotional disabilities to the first article, focusing on each of Balow's issues critically. The fourth article, "Autism--A Legislative Issue," presents the content of a state resolution passed jointly by the Iowa House and Senate in 1980 regarding the development of special programs for autistic pupils. (DLS)

****
* Reproductions supplied by EDRS are the best that can be made *
* from the original document. *
****

- ED193822

U S DEPARTMENT OF HEALTH, EDUCATION & WELFARE
NATIONAL INSTITUTE OF EDUCATION

THIS DOCUMENT HAS BEEN REPRODUCED EXACTLY AS RECEIVED FROM THE PERSON OR ORGANIZATION ORIGINATING IT. POINTS OF VIEW OR OPINIONS STATED DO NOT NECESSARILY REPRESENT OFFICIAL NATIONAL INSTITUTE OF EDUCATION POSITION OR POLICY

"PERMISSION TO REPRODUCE THIS MATERIAL HAS BEEN GRANTED BY

Carol L. Smith

TO THE EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)."

IOWA PERSPECTIVE

News of Programs for Emotionally Disabled and Chronically Disruptive Students
Iowa Department of Public Instruction

May 1980

Current Issues in Programming for Autistic Children and Young Adults

Bruce Balow, Ph.D.
Department of Psychoeducational Studies
University of Minnesota

When discussing issues in programming for autistic children, one can approach the topic from a variety of levels: highly theoretical and somewhat arcane to completely practical; and one can focus upon highly specific, narrow matters or sweep broadly, hitting the high spots. This article will deal with issues that I regard as highly practical for educators and will touch upon several that I regard as important, rather than treating one issue exhaustively.

The article examines six issues. Four of them are essentially professional and two are in the "real world." The four professional issues are: 1) Who is this person called autistic? 2) What is the best placement? 3) How do I figure out the program needed? 4) What treatment style should I use? The real world issues are: 1) cost effectiveness and 2) influence on policy and politics.

Who is this person called autistic?

Everybody knows and nobody knows. I recently had the opportunity of working with several professionals identified as experts on autism and found that one of them could not accept the notion that autistic children could possibly be verbal or could have enough social skills to be integrated with non-handicapped children in the public schools.

Such children, to his way of thinking, were wrongly diagnosed as autistic; he showed no difficulty whatsoever in simply dismissing the judgments of a group of skilled professionals who believed that the children they worked with were indeed autistic. To him, a group of autistic children could not have language, could not function in groups, and could not be integrated with non-handicapped children in school. To him, the autistic child was clearly and very narrowly defined. Such a child had to have severe problems with language and communication (preferably having no language at all, or at best, being echolalic), be severely retarded in functional behaviors, show bizarre behaviors and strongly demonstrate the characteristic of autistic aloneness.

Historically, autism has been considered similar to, if not indistinguishable from, childhood schizophrenia and certainly one of the psychoses. Increasingly, however, people are suggesting that it is far more similar to severe and profound retardation than to emotional disturbance. Also, by reason of suspected etiology, course of the syndrome and likely long-term future, it is more clearly a severe functional disorder with physiological causation than an emotional disorder.

Consider the literature on autism and the enormous disagreement about the diagnostic signs characteristic of autism. In 1971, DeMyer and others made a comparison of five systems of diagnosing autism and childhood schizophrenia and showed that the different systems overlapped no more than 35 percent, although they were significantly correlated (DeMyer, 1971).

Leo Kanner, who originally described the syndrome of infantile autism in 1943, listed 12 characteristics of which four were judged to be of particular importance. These were extreme autistical aloneness, an obsessive desire for sameness in the environment, stereotypical or repetitive actions, and echolalia (Kanner, 1943).

Creak (1961, 1964) proposed nine characteristics

In This Issue:

"Current Issues in Programming for Autistic Children and Young Adults" by Bruce Balow

"A Parent Responds" by Nicole Raaz

"An Iowa Professional Responds" by Polly Nichols Arp

"Autism: A Legislative Issue"

EC130142

for "schizophrenic syndrome in childhood," with two of the nine of major importance. These were gross and sustained impairments of emotional relations with people and serious retardation with islets of normal or above normal skill.

DeMyer indicated that the schizophrenic syndrome in childhood about which Creak wrote is essentially what other writers have called autism. Rimland (1964) has also put forward nine characteristics of autism and selected two as major indicators; these are autistic aloneness and insistence on being left alone in an unchanging environment. Five diagnostic indicators of autism were listed by Rutter (1969), who highlighted the problems of relating to others, distortions in the language and stereotypical or repetitive behaviors.

These groupings of diagnostic criteria, according to DeMyer, show that 35 percent of the descriptors identifying the syndrome are the same. Beyond this limited agreement, it should be clear that each of these definitions is simply an aggregate of descriptors. Thus, at this point all the major definitions are simply lists of signs or symptoms, showing general agreement at the core but much disagreement on the edges.

From the standpoint of selecting a categorical group or special class, how much of any one characteristic does a child need to exhibit to be considered autistic? How often must a child show a particular sign or symptom? Is the child autistic if he shows two out of nine, or three out of five? Does it matter whether the chld shows one or two major symptoms and none of the minor ones? Is a child who is considered autistic according to Kanner's system also considered autistic by a person following Rimland's criteria? If child "A" shows the first three symptoms of the Creak British Working Party list and child "B" shows the last three, but no overlapping symptoms are found between them, are both autistic? Is neither autistic? As we professionals exercise our judgments about children suspected of being autistic, it should be clear that we are dealing in guesswork, not science.

Finally, in the matter of definition, even if we could agree on one specific set of descriptors, the problem of how much a child shows a particular characteristic is still at issue. Rarely will you find a description of a group or class of autistic children which indicates with any degree of precision the extent to which each child shows the various characteristics claimed to represent autism. Individual differences between and among such children are obviously large.

The issue, of course, is that we really are not clear about who we're talking about. In view of the definitional problem, unsolved after 35 years and unlikely to contribute much to programming decisions anyway, what is the point to focusing on narrow interpretations of signs and symptoms? It is sensible, for programming, only if one believes a homogeneous group will result and that that will simplify treatment. I doubt we can get there from here.

The alternative to forcing a child/label fit and responding to stereotype by narrow ranges of placement is a functional analysis of the individual child's needs. We will come back to this a bit later.

What is the best placement?

Low incidence and a current bias against separate state facilities for severely handicapped persons largely, but not totally, eliminate some standard "solutions" that were widely used in the past. State hospitals are a far less common choice of placement for a severely handicapped child than was true even 10 years ago. In Minnesota, for example, in the past decade the number of retarded persons in state institutions has dropped by half and new initial placements are few.

The self-contained special class has also fallen out of favor in the last several years in response to the "normalization" principle and the notion that separate cannot be equal. Federal court cases and national and state legislation now generally push for least restrictive placements; for school age children that generally means the regular public school. For children with severe, low incidence handicaps, such as autism, there is still a tendency to try to arrange a self-contained, separate placement, but if a given autistic child is the only one in town, or in the region, there is not likely to be an "autistic class" readily available. Nonetheless, there often will be strong attempts made to arrange such a class locally or in a neighboring region.

The pressures to move away from segregated special placements are highly desirable. Making such placements extremely difficult to obtain precludes the unthinking, stereotypical response to autism. In the absence of segregated placements, we professionals are forced to carefully analyze the functional behavior of the child and plan a specific program that fits the particular child's special needs. It may be that such an analysis will lead to more creative planning for the child: considering placement in programs for the severely retarded, for the mildly retarded, for behavior problem children, in a regular class of the same age or younger age children, or even a step-wise program that begins with individual tutoring of the child and then gradually leads into broader and broader group placements. But, the important thing is that the placement decisions are based on the individual child's behavior, not upon the label "autism", and not upon an available, existing, segregated special facility.

Are there enough similarities in children and enough constraints on resources to support attempts at homogeneous group placements? Certainly! It is quite possible to group children, particularly in flexible groups that come together for brief periods of time on the basis of relative similarity in functional needs, but certainly not on the basis of diagnostic labels or categories of handicap.

Obviously there are increasing constraints on resources even for handicapped children. In the absence of unlimited amounts of money to program as one might wish, it does make sense to attempt the most cost-efficient system within good professional practice. And, part of the issue of placement is whether collecting bizarre behavior in one place really helps the children, or whether it simply makes it easier on resource expenditures. If it is true that bizarre behaviors trigger outbreaks in other children,

it would not seem to be the most sensible move to collect such children in one room. Further, autistic children are very slow on giving rewards to their teachers. Thus, it is an unusual adult who can work with such children month after month without feeling the need for some reinforcement himself. By mixing children a bit so that more normal-behaving children are included, the likelihood of the teacher "burning out" is considerably reduced.

How do I figure out the program needed?

The typical pattern of sending the child off for intelligence scores and a psychological and medical assessment is of relatively limited value. Such assessments clearly have a place, largely to rule out physiological disorders that are medically treatable, but they are mostly irrelevant to the question of educational programming. What is needed is an analysis of the child's behavioral patterns; once again, a functional analysis of the child's behavior. What can the child do and under what conditions? These questions must be answered for all the relevant dimensions of education including: a) social interaction, b) self help skills, c) language, d) preacademic and academic skills, and e) "person-ness".

Most of those items are self evident and do not need a great deal of explanation. However, all of them need careful analysis so that the teacher will be able to plot a program of instruction leading to improvements in: dealing with others, personal care, communicating with others, preacademic and academic skills of listening, attending, following directions, and related items.

The matter of "person-ness" is more difficult to discuss, but I believe it is as important as any other item. It is not enough that we train the child to respond as a dog responds to his master's command; we're not looking for responses of an automaton. We need to encourage choices, the expression of self, volitional eye contact rather than command eye contact, the use of language with inflection, responses to other human beings as a human being. To do that most effectively requires, I believe, a close personal relationship with the child along the lines that the Freudians and the phenomenologists would regard as appropriate. Personal regard and trust can be learned by autistic children and when learned, it will often be returned to others. It is as difficult as the other items to teach, perhaps more difficult, but it is also fully worth the effort. (See, for example, Stuecher, 1973)

There is less doubt about identifying a child's skills and abilities along such dimensions than there is about what resources to use for the child. That is, analyzing need patterns is relatively easy compared to figuring out how to get necessary services, because services translate to resources and resources translate to money.

The kind of frustrating problem that arises, for example, is that you may be generating a highly successful program for an autistic child who is being transported to your program at a cost of $50 to $100 per day. Suddenly, someone determines that the child is not eligible for such transportation support and must be removed from the program simply because nobody has $50 or $100 a day to pay for such transportation. An interesting aside is that such children are being educated for something on the order of $25 a day or less, yet complaints tend to be about the high costs of instruction, not transportation.

What treatment style should I use?

Probably the three major issues in educational treatment are: 1) professional versus parent instruction, 2) whether the method applied is to be pure or eclectic, and 3) what the nature of the curriculum should be. It was a professional catechism a few years back to exclude parents from treatment, partially in the belief that they were to some extent a major factor in creating and maintaining the problem, and therefore not likely to be constructive in a treatment program. Those ideas have pretty well fallen by the wayside, and most programs now rely very strongly on parents as a major part of the treatment program. Whether the child needs assistance in learning to feed herself, dress herself, communicate appropriately, or anything else, it is clear that a six-hour, or less, school day is unlikely to make rapid progress with autistic children. Therefore, recognizing that parents are with their children many more hours in the week than are the professionals, it makes sense to try to cooperatively develop a program and cooperatively carry it out, with consistent attention to items of importance and consistent instructional and reinforcement procedures, whether the child is in school or at home.

Methodologies tend to fall into three major categories. Those are: physical treatments such as drugs, diet, or end organ manipulation; one of the conditioning therapies or stimulus-response learning theory treatments; and some type of humanist or psychoeducational treatment. As methodologies, all of them would seem to have a place and may be reasonable for selected children and for selected objectives. However, I believe the nature of the problem and the evidence that does exist would argue for an eclectic methodology, applying the best elements of humanistic treatments, the strengths of stimulus-response learning theory methods and, where necessary for a specific medical problem, the inclusion of a physical control mechanism.

Finally, the matter of curriculum should be relatively obvious, although once again we find professionals pursuing content that seems to have no sensible place in that particular child's world at that particular time. That is, every autistic child needs an individual curriculum, specifically built according to a ranking of his particular needs, which are quite likely to fall into the five categories I previously described. However, it makes no sense to block out sizable amounts of time for academic instruction of an autistic child who is unable to communicate.

The Real World

From an admittedly biased view of the professional issues, I have suggested a number of beliefs, viewpoints, and actions. But, the major factors in the decision process may not be

professional at all, but political. Those political matters fall into two territories of further issues: first, issues of cost effectiveness. Throughout all of the decisions about placement, diagnosis and treatment, cost constraints intrude unhappily (but realistically).

The professional recommendation for a particular autistic child may well be that the child would best be served in a placement which turns out to cost $40,000 per year. It is almost certain that the child will not be placed in such a facility under public monies. It is almost equally certain that the professionals involved will not make such a recommendation, even though they believe it is in the best interests of the child, simply because of what they believe are the administrative/resource constraints facing them.

Teams that are constructing individualized educational plans for handicapped children these days oftentimes set their sights only on what is available in the local school building, or possibly in the school district, but rarely do they start with the child's needs (as the law demands) and recommend what the child requires regardless of local or regional availability. It is, in fact, the professional's responsibility to describe what is, in her best judgment, required to help the child attain whatever goals are judged possible. Then, it is the administrator's responsibility to worry about how or where those particular resources may be obtained. However, our typical practice is to trim the recommendations so that no one ever knows what the optimum circumstances might be for the given child.

Realistically, the public is not willing to provide unlimited amounts of money to educate or train one child and increasingly, as the economy turns downward, the tendency is quite noticeable that calls for cost cutting. Recently in Minneapolis, for example, a duly established board of decision makers was faced with a request to expand a "group home" from roughly 100 mentally retarded residents to approximately 200. After due consideration, it decided to recommend approval of that expansion, despite many arguments from concerned groups that such an action is totally contrary to the normalization principle. It is impossible to establish a homelike atmosphere in an institution holding 200 people, they said.

The major argument on the other side was simply that the cost effectiveness of such a facility was so much greater than paying for small group homes that the decision makers would be derelict in their duty to the public if they did not approve it. They estimated that the large facility would save the taxpayers on the order of $400,000 per year. That may well be an appropriate administrative decision, but it does not appear to be an appropriate decision to be made by professionals whose primary responsibility is the further development of mentally retarded persons.

In the matter of real world constraints on treatment, it is often that the best treatment program for an autistic child may call for full time one-on-one instruction, at least for a period of months, in a somewhat specialized setting with multiple opportunities for integration with non-handicapped children. But, how often can that be obtained? That is, paid for? Even for a relatively short period. It is one thing for administrators to reject a claim for treatment of that sort based on cost effectiveness, even though they may well be misguided. However, it is a much more serious problem when the professionals making the recommendations cut back those recommendations simply because they believe that the administrators are going to reject their request or that the particular resource is not available locally. I believe it is our responsibility as professionals to make the fullest and most complete recommendations that we can for realistic development of the child, and if the resources to meet them are not available, as they often are not, to argue strongly for the best compromise that we can get. But, we ought not to start with the compromise.

Finally, there are issues of influence on policy and politics. One policy decision along lines favorable to programming for autistic children, for example, would make far more difference to far more autistic children than would a year's worth of assessment teams and carefully developed IEPs. The policy decision at the national level to include autism in the definition of developmental disabilities, and therefore to make autistic persons eligible for whatever resources were allocated under that federal law, was far more important than years of professional effort.

Programming for autistic children is probably best done on the basis of aptitude by treatment interactions, without the need for any label and without the need for any categorization of children. But, influence at policy-making levels tends to come from identifiable groups which carry labels, and which can play the politics of special interest groups. Knowledgeable people need to push hard in both the academic and political worlds since there is much to be decided and much to be done in each.

References

Creak, E. M. Schizophrenic syndrome in childhood: Progress report of a working party. *Cerebral Palsy Bulletin*, 1961, 3, 501-504.

Creak, E. M. Schizophrenic syndrome in childhood: Further progress report of a working party. *Developmental Medicine and Child Neurology*, 1964, 6, 530-535.

DeMyer, M. K.; Churchill, D. W.; Pontius, W.; & Gilkey, K. M. A comparison of five diagnostic systems for childhood schizophrenia and infantile autism. *Journal of Autism and Childhood Schizophrenia*, 1971, 1, 175-189.

Kanner, L. Autistic disturbances of affective contact. *Nervous Child*, 1943, 2, 217-250.

Rimland, B. *Infantile autism: The syndrome and its implication for a neural theory of behavior*. New York: Appleton-Century-Crofts, 1964.

Rutter, M. A tri-axial classification of mental disorders in childhood. *Journal of Child Psychology and Psychiatry*, 1969, 10, 41-61.

Stuecher, Uwe. *Tommy: A treatment study of an autistic child*. Reston, Va.: Council for Exceptional Children, 1973.

A Parent Responds

by Nicole Raaz
Mason City, Iowa

Many parents view the discussion of current issues in programming for autistic children as a waste of time and effort—a case of everyone talking about a problem, but no one *doing* anything about it. And, for the parent whose child is literally screaming for hours at a time each day, rocking and head banging, or doing a number of other bizarre things that we, as parents, come to regard as typical, this type of discussion may seem useless.

However, it has been five years now since the law guaranteed our children an appropriate education based on their individual needs, and that isn't happening. If the situation is to change, there must be an identification of "why". What are the problems in programming effectively for this population? Hence the discussion of issues that affect programming for autistic children. Personally I'm pleased that this type of discussion is taking place in professional circles. It is better to raise the issue for discussion than to completely ignore the subject of programming for autistic children.

Identification has always been a problem. Over the years a number of diagnostic instruments have been developed to identify the autistic population and, as Balow points out, there has been disagreement among those working in the field as to which characteristics a person must have in order to be considered autistic.

In an attempt to clarify the issue of identification, the Professional Advisory Board of the National Society for Autistic Children (NSAC) in 1977 developed a working definition of autism which combined the most current medical research findings with the traditional lists of characteristics to arrive at a descriptive definition that the members of the Professional Advisory Board, as well as the NSAC Board, could accept.

The definition describes four essential features which "are typically manifested prior to 30 months of age and include disturbances of: 1) developmental rates and/or sequences, 2) responses to sensory stimuli, 3) speech, language and cognitive capacities, and 4) capacities to relate to people, events, and objects." (Ritvo, 1977) The long definition describes more fully each of these four features and the types of behavior that may be observed as they relate to each of the four essential areas of disturbance. Associated features are also described with the notation that these may vary with age. Autism is compared with other disorders in a segment on differential diagnosis. The etiology that is offered is that "the symptoms are best explained as expressive of a physical dysfunction within the central nervous system—the exact nature and type of which has yet to be determined." (Ritvo, 1977).

The four essential features and the associated features are descriptive of the characteristics previously offered in the diagnostic lists Balow mentions, but this definition goes far beyond simply listing signs and symptoms. This definition also gets us past the question of how much of a particular characteristic a person must have. A person is considered to have the disability of autism if he or she has disturbances in the four essential areas. How much of each is not an issue. We accept the varying degrees of other medical disabilities such as mild or very severe cerebral palsy and all degrees in between. In education, too, some children may have a mild form of learning disabilities while for others, the problem is more severe.

Yet, Balow seems to imply that with autism it must be an all or nothing thing—either a child is or isn't autistic. There is a wide functioning range of autistic children and there are individual differences among the children, but that is also true for other disability groups. I believe that if autism is viewed in terms of the NSAC definition, we are closer to identification of a homogenous group of children than Balow implies. These are children whose needs are similar in four specific areas and these needs must be met if we are to program appropriately for them. I am reinforced in my belief each time I talk with another parent of an autistic child and find that our kids, even if functioning at different levels, are more similar to each other than to children with other disorders or to those who are considered to be normal.

As to Balow's statement that "we are dealing in guesswork, not science" with regard to identification, I prefer to think that we are going through the same learning process that we have in every other field. Medical definitions of most disabilities have changed over the years as new information is obtained. The same is true in education. The definition of emotional disability has been revised at least once in Iowa since 1975. I don't think it is guesswork simply because every professional has not agreed with the original definition offered by Leo Kanner in 1943. I was told at the time of my son's diagnosis that there has been a lot of incorrect information written about autism. Over the years I have learned to use my own judgment to compare what I read (or what I am told by professionals) with what I know to be true about my son and the other autistic children I have known.

For professionals who have no experience with autistic children, or those who are looking for pat answers to all of the questions before they enter the field, this disagreement may present a problem. But, I would encourage professionals, as I do other parents, to use their best judgment based on a comparison of the most current information available and what they know to be true from working with these children. We must allow ourselves the flexibility to change our beliefs as new information becomes available because that is how we learn.

I must also take issue with Balow's contention that the definition of autism is "unlikely to contribute much to programming decisions anyway. . ." It is my belief that defining autism and identifying children according to a specific criteria do have implications for programming. Teachers of children with special

needs receive training which will prepare them to better serve those children. Apparently it is believed that if a person has a better understanding of a specific disability and how to teach children with that particular problem, she or he will be a more effective teacher. If not, we would have no categorical certification of teachers—any teacher with a special education degree could teach any child with any disability. That is not the case in our state.

I believe that the same principle is true with autistic children. Understanding the autistic child's disability gives the teacher more information to use in the problem solving that leads to programming which will be effective for that child. The label "autism" does mean something educationally. Each child's program will have to be modified to meet the child's individual needs, but knowing that the child is autistic will give the teacher more information with which to work.

For example, take the functional problem of lack of speech. Many kinds of children do not speak: some children who are retarded do not speak; some children are aphasic; some children who are hearing impaired do not speak; and some children who are autistic do not speak. They all have the same functional problem, but it is important for treatment to have the other information about the possible reason for the lack of speech. A clinician, through behavior modification, can teach the autistic child to use language. But, it is essential for the clinician to also know that children who are autistic have difficulty attaching meaning to spoken language and generally have good rote memories. For the child to give a response is not enough. Knowledge of autism lets the clinician know that meaning must also be stressed, that comprehension must be checked continually, and that the transfer of language to functional use in the environment must take place. Analysis of functional behavior is important, but the label can also serve as a guide in programming.

The push in our state for identification of autism as a separate category is not because parents want their children in classes only with other autistic children. It is because this recognition of autism emphasizes that these children have educational needs different from children in the other categories. With a separate category, specific teacher training can be required. The teacher would then have the "background information" on autism needed to teach our children. Much time is wasted for both teacher and child as each teacher must "reinvent the wheel" as he or she tries to figure out what may work for the autistic child who has been placed in the class. The best teacher is the one who had good problem-solving skills—who can look at the functional problem and figure out what is needed. But not all teachers are good problem solvers. So, it is important for all to have as much information as possible to help them learn to help our kids.

Balow states that, "in the absence of segregated placements, we professionals are forced to carefully analyze the functional behavior of the child and plan a specific program that fits the particular child's special needs." He goes on to state, "such an analysis will lead to more creative planning for the child..." How I wish that were true! Unfortunately what is happening is that since special autism programs do not exist in most parts of our state, the autism part of the child's disability is ignored. Our children are placed in mental disability programs according to IQ, or in emotional disability programs if behaviors are difficult to manage. The teachers in those programs have the "background information" in mental disability or emotional disability, but do not understand, until the child has been in the class for awhile, that the autistic child learns in a way that is different from children with other disabilities. Balow stresses, "the important thing is that the placement decisions are based on the individual child's behavior, not on the label autism..." I agree, that is the way it should be, but since that so rarely happens, for my child I would rather take my chances with a program based on the label autism than one based on some other label.

With regard to placement, the collecting of bizarre behaviors in one place doesn't have to be a problem if, as Balow suggests, a mixture of children are grouped together. One argument that is often used as a reason for not developing "autism classes" in the more rural parts of our state, is that there are not enough children who are functioning at the same level. It is probably a better grouping if they are not all functioning at the same level for the reasons Balow cites. Locating such a class in a regular attendance center offers the flexibility of integration of the children with peers in regular education classes and the chance for many more normalizing experiences for all of the children in the special class.

The dimensions of education that Balow identifies as priorities are those that I also would choose, with communication skills and "person-ness" at the top of my list. I have come to feel that the most important skill we can give a child is the ability to communicate with the world around him or her. The ability to make wants known, to attain a degree of control over what is happening to him or her, and to use those communication skills to reach others will aid in the development of the quality Balow describes as "person-ness". With the methods that we traditionally have used in programming for autistic children, that is, behavior modification, there is the very real possibility that our children will become reactors or responders, but not initiators. To teach a child skills without also developing the human qualities that will make the child want to use those skills to participate in the world, is indeed sad.

Of course the argument can be made that to teach a person to function in a mechanical manner is better than allowing him to rock his life away in an institution, and that is true. However, I feel that we can do better than that. It isn't an easy task, but it can be done.

With regard to treatment style, I am a firm believer in parent involvement in education. The following statement was offered recently in a professional publication, "the purpose of school is to train people to function in other environments besides the school environment" (Maurer, 1980). What you teach a child in the classroom does him or her little good if those skills do not carry over to the rest of his or her world.

And, as Balow points out, since the autistic child is unlikely to make rapid progress in a six-hour, or less, school day, it would seem logical to include parents in the program planning, to arrive cooperatively at goals for the child, and to try to achieve those goals in both settings.

I hear from professionals that some parents are uncooperative. I hear from parents that school personnel are unrealistic in their expectations. I know that unless there is cooperation, it is the child who looses.

Since it is probably easier to manage the child for six hours a day in a classroom than for 18 hours a day while also trying to live the rest of your life, my sympathy lies, most often, with the parents. It is the parent who will be involved with the child for most of the rest of his or her life, so I believe that the parent should play a very important role in the decision-making process with regard to the child's program. But, there is a need for persons on both sides to carefully listen to each other and to think always of the child. Thus, the goals set for the child will be those that will maximize his or her chances to lead a meaningful life.

As an observer of the education scene for almost 10 years now, I have moved from a strict behaviorist viewpoint on methodology to favoring now, as Balow suggests, an eclectic methodology which uses the best elements of each of the approaches. I believe that there are probably a number of different causes of this brain disorder that we see in the autistic child, so different methods may be needed for different children at different times. I also feel strongly that diet may be a key to helping some types of autistic children. Megavitamins may work with others, and other treatment methods may help some children. No one treatment will work for all children. Since there is no one answer, it is, again, up to the professional, and the parent, to use his or her own best judgment.

For most of the discussion Balow has dealt with the professional world—how things should or could be. With a number of his issues, I have tried to point out the reality of what is happening compared to how it theoretically should be.

With the issue of money, however, we all enter the real world. It does cost a lot to educate our kids, but the cost doesn't seem so great when you consider the alternative. If we fail to provide an education that is appropriate, this generation of autistic children will join the 95 per cent of the adult autistic population who are housed in our state institutions. The cost is also great to keep someone in an institution. Education is the only hope that these children have. To start with a compromise, rather than the most appropriate educational option, when making program recommendations may mean the difference between a meaningful life and no life for the autistic child.

The real world is political. Decisions that affect services for kids are based on policies that can be influenced by special interest groups. My advocacy, and that of others in the NSAC, is based on the belief that the system should work for all children. Both parents and professionals can advocate for individual children, but those without an advocate will miss out. It is easy to "lose" our children in the system. It is difficult and costly to serve them appropriately. But we owe to each child the chance for a meaningful life. Only by working together, parent and professional alike, by establishing an identity for autism, and by developing a strong voice to make our children's needs known, will we be able to make the system responsive to the needs of each child.

References

Maurer, S. (Ed.) *Iowa News, Severely and Profoundly Handicapped*, Des Moines: Iowa Department of Public Instruction, February, 1980.

Ritvo, E. R. *National Society for Autistic Children, Definition of the Syndrome of Autism.* Unpublished paper. Washington, D.C.: National Society for Autistic Children. 1977.

About the Contributors:

Bruce Balow is professor of special education at the University of Minnesota. His professional work includes a wide range of experiences in teaching and psychology. In addition to his teaching experience and university affiliations, he was, for two years, director of the Division of Training Programs, Bureau of Education for the Handicapped, U.S. Office of Education. Dr. Balow has published numerous professional articles dealing with such topics as training teachers of the behaviorally disordered, longitudinal studies of children with learning and behavioral problems and autism.

Nicole Raaz presently resides in Mason City, Iowa. She is editor of LINK, a newsletter dealing with autism and is currently president of the Iowa Chapter of the National Society for Autistic Children. Ms. Raaz's son, John, is 12 years old and has been diagnosed as autistic.

Polly Arp is supervisor of emotional disabilities for the Grant Wood Area Education Agency in Cedar Rapids, Iowa. Ms. Arp has an extensive background in the areas of autism and emotional disabilities including teaching and research experience in the Child Psychiatry Department of the University of Iowa and public school teaching and administration. Ms. Arp is a Ph.D. candidate at the University of Iowa.

An Iowa Professional Responds

Polly Nichols Arp
Supervisor - Emotional Disabilities
Grant Wood AEA

My response to Bruce Balow's paper will be distinctly Iowan. Balow's thoughtful discussion of four selected professional issues and two "real world" ones stimulated my thinking on our own small corner of the real world. Educationally speaking, Iowa is a stand out — the nation's most literate state, known for its landmark social and educational programming. But, it is also among the nation's most rural states, and we have special problems dealing with low-incidence handicaps in our sparcely populated areas. How will we, in Iowa, act upon the critical elements of Balow's four issues — appropriate classification, program placement, curriculum, and methodology — in light of the real world concerns of cost effectiveness and public policy?

Autism has risen to the surface of public awareness today in much the same way as learning disabilities (LD) did a dozen years ago. Today, more students receive special education service under the categorical heading of LD than under any other. No one suggests that there is anything like that number of autistic children to serve, although some researchers are suggesting that the incidence of autism may be closer to 12 or 14 per 10,000 rather than the currently accepted rate of 5 per 10,000. What is similar, however, is that parents of autistic children have found each other, and their collective voices have garnered strong professional and public support for programming to meet the needs of their children.

An inevitable tension develops. Parents and professionals focused primarily on this disability stress its uniqueness, its special characteristics that set autistic children apart from those with other emotional, mental or language disabilities. Pulling against this is the emphasis that special education generalists place on the ways in which children are more alike than different, on the components of teaching exceptional students that transcend categorical labels. Balow speaks persuasively to this latter point of view; the parents in the Iowa Society for Autistic Children (IaSAC) strongly advocate the former.

Perhaps in Iowa this seems a moot point. It may be conceivable to think of categorical programming in the 11 county area surrounding Des Moines where, using the theoretical 5 per 10,000 number, there should be about 60 autistic school-age children. But what about the seven youngsters presumably scattered somewhere in Area 14's eight counties? No one can reasonably expect these seven to be grouped sensibly by age and functional level into one or two special autism classes.

We need to bear in mind this central principle expressed by Balow: ". . . it is our responsibility as professionals to make the fullest and most complete set of recommendations that we can for realistic development of the child, and if the resources to provide that are not available, as often they are not, to argue strongly for the best compromise that we can get. But we ought not start with the compromise." I will add a correlary principle: It is our responsibility as professionals to see that autistic children are not simply adequately "maintained" but are placed in educational settings where they will be expertly taught.

To begin with Balow's last point first, I would like to suggest that we can have influence at policy-making levels by serving autistic children as an identifiable group, complete with label, and that this need not be a necessary evil, an expedient capitulation to "the politics of special interest groups." By serving them as members of an identifiable group, even when we serve them as individuals in groups bearing other labels, we will not compromise our responsibility to meet their unique needs. For, I believe that autism is unique and that the constellation of handicapping components that sets it apart from other special education designations has direct implications for specific programming.

A cost-efficient way of assuring that theoretical program specifics find their way into every autistic child's school day is to assign responsibility for doing so to an autism advocacy position within the AEA structure. This person or persons would have a central focus of interest in and the best available training for working with autistic children, their families and others who serve them. This expertise would prevail whether the programs were designed for the autistic or for the emotionally disabled, mentally disabled, profoundly disabled, or normal children. On the one hand, this person would centralize concerns, drawing the children's disparate needs and the scattered facilities for meeting them into a cohesive whole; on the other hand, he or she would provide a mechanism for outreach from specific classrooms to the broader circles of area parent groups and social agencies and from there to state and national centers of research and service.

Balow's Issue 1 — "Who is the person called autistic?"

Public Law 94-142 lists autism specifically under the heading of seriously emotionally disturbed. The new DSM III, the classification system of the American Psychiatric Association, classifies autism as a developmental disability. A summary of the official National Society for Autistic Children definition calls it "a brain disorder manifested as a form of sensory impairment" and defines it educationally as a series of deficits in "all aspects of communication." Depending on program availability and professional emphasis therefore, one could classify the "primary disability" as emotional or as mental. One could certify a child as needing a self-contained class for the severe and profoundly

handicapped or as requiring resource room assistance with mild handicaps or, conceivably, as requiring no program placement at all.

None of these options is patently bad nor is any complete appropriate. As Balow clearly substantiates, no list, no aggregate of descriptors will define autistic children so clearly that having labeled them, we will know how to educate them. A functional analysis of the individual child's needs will indeed be the key determinent of all that follows — but the fact that the concept of autism is complex and its manifestations various does not make it a useless designation. We will never know "who it is we're talking about" if we expect to find one consistent and stable entity, a singular "who". If we understand the plurality of this "who" as representing a wide range of individual characteristics that sort down into a particular constellation of central deficits, we can relate our functional analysis to a body of literature that will allow us to study what works and what does not with similarly impaired children.

I would like to see more, rather than less, effort expended on defining the characteristics of autism in educationally relevant ways and I believe this should be a central goal of autism advocacy. I know that AEAs 11 and 13 have worked on this intelligently from very different perspectives, and this diversity is wholesome. It would be superb, however, if we could develop a *consistent data base* throughout the state to help us better evaluate how various program models and teacher characteristics interact with various functional characteristics of autistic children. The Autism Screening Instrument for Educational Planning (ASIEP) by Krug, Arick and Almond has recently been published. It combines a behavior checklist, a sample of vocal behavior, a structural observation of social interaction, an educational assessment of functional skills, and an analysis of learning rate. Such an instrument offers the possibility of making meaningful recommendations for individuals and comparisons across Iowa's diffuse autistic population. Inevitably, one professional's theory of what should be assessed will differ from another's, but at least we can objectively look at how one autistic child's characteristics compare to another's and consider how the range of such children can be best taught. The instrument would also offer the educational community a means of evaluating a child, whether or not a full psychiatric evaluation was available or acceptable. A system of autism advocacy would assure the availability of a trained assessor to each AEA. Given the low number of autistic children in the state, total screening would be much less overwhelming a task than giving two days of Iowa Basic Skills Tests to all of Iowa's school children!

Balow's Issue 2 — "What is the best placement?"

No reasonable person could take exception to Balow's basic thesis that placement decisions should be based on a child's functional needs, just as no reasonable person will deny that it is impossible to have autism classes available to all autistic children. I do not think it follows, however, that there should be no autistic classes available to any autistic children.

Most autistic children are served in classes designed primarily for others at about their developmental level of intelligence. With an advocate to assist the teacher in adjusting the instruction to the child and secure whatever additional resources might be necessary, this may be an entirely appropriate setting. There should be, however, a network of classes throughout the state where educational programs designed to be particularly appropriate for autistic children can be developed, implemented, demonstrated and evaluated. The first points along such a network already exist.

Will a network of such classes encourage an unthinking, stereotypical response to autism? Not, I believe, if they are implemented as one element of a total autism advocacy approach. The data seem clear that carefully organized classes for autistic children such as Ft. Madison's and Mason City's landmark programs are indeed effective. If they are not perceived as the *only* model and if other settings are specifically adjusted to provide meaningful educational service, they needn't become the knee-jerk option for all autistic children that Balow fears.

Balow's Issue 3 — "How do I figure out the program needed?"

I disagree with Balow's dismissal of psychological and medical assessments as being relatively useless and largely irrelevant to questions of educational placement. The more one knows and the more precisely one knows it, the more deliberately one can plan appropriate instruction and the more clearly one can check the amount and rate of improvement made. In fact, I think this may be more critically important for autistic children than for many. Autistic children have uneven developmental profiles with behaviors and splinter skills that stand out and that suggests across-the-board capabilities or deficits. An experienced diagnostician can best identify and communicate these.

The 13-year-old who word-calls at grade level but comprehends little and has social behaviors that are atrocious may have unreasonable demands made on her. Systematic assessment will assist everyone in perceiving where she functions more like a four-year-old than a teenager and will encourage more thoughtful planning of teaching strategies. These children are tough to evaluate, and I support using all the help we can get from wherever we can get it.

One telling way of thinking about the issue of best placement is to consider age as variable. Specific programming for autistic children makes especially clear sense in the earliest educational years. Early intervention is desirable for all handicapped children, but for none more than for autistic children. For example, consider the contrast between what is routinely offered in a regular pre-school curriculum and what is needed by autistic pre-schoolers. The self-discovery, exploratory, free-play-oriented approach so rewarding for most three and four-year-old children offers little to the autistic child. She literally does not know how to play alone or with others, and her lack of ability to make believe and deal with

symbols shows up as a cognitive deficit. On a pragmatic level, the grouping of autistic children works better when they are all young and developmentally closer to each other than when their full range of intellectual and social levels spreads out in middle childhood. As adolescence approaches, new concerns rise to the fore as specific preparation for whatever level of job and living independence will be manageable must be *specifically* made.

Balow's Issue 4 — "What treatment style should I use?"

I certainly concur that physical treatment, operant techniques and humanistic qualities all have their place in programs for autistic children. I sense that my mix might look rather different from Balow's. His warnings that we are not to expect autistic children to respond as trained dogs or automatons and that we focus on "person-ness" suggest that he has had bad experiences with behavior modification that I have not had. Certainly the teachers I know who use learning theory as a theoretical base are bound in close personal relationships with the children they teach, and I am sure that this combination is at the heart of Balow's call for an eclectic approach.

I would summarize the critical elements of instruction for autistic children in these "in" words: It must be highly *instructional — what is to be learned must be directly taught to criterion, not left to chance interactions with the environment. It must be highly intentional* — many more trials on each task, much more consistent direction, and much grander use of gesture and of consistent verbal cues are needed than with other children. It must be highly *intrusive* — the teacher must insist on "moving into" his autistic students and constantly engaging them in positive interaction with him and his world.

Autism Advocacy

I have used the term "autism advocacy" rather than "autism advocate" because I do not believe that such an advocacy role can be adequately filled by educators alone. The needs of autistic children and of their families extend far beyond the school day and the school years. The challenge of meeting them must be faced by society in general, all phases of it.

An autism advocacy plan could help centralize these concerns, give them shape, direction and support. It could provide a cohesion among parents, a way for them to share their experiences, joys and anguish. It could provide a mechanism for teachers of autistic children, whatever educational discipline they come from, to communicate with colleagues who are working with similar children. It could help establish a network of model programs that are reasonably accessible to all of those involved with autistic children. It could gather and coordinate data and disseminate information throughout Iowa and beyond. In short, it could pull the 163 scattered Iowa children and adolescents currently identified as autistic into a meaningful group for sharing and development.

Many issues must still be addressed. What kinds of preparation for teaching these challenging children will result in the best educational payoffs for them? What mechanisms for sharing the exhausting 365-day-a-year responsibility for serving autistic children with other agents of the community can be developed by schools and families? As a first step toward meeting such goals, the AEA's can develop a cadre of the most experienced and interested professionals from its ranks of school social workers, speech personnel and consultants. Given the task, adequate time to devote to it, and ample opportunity for professional growth, such an autism advocacy group could see that Iowa's autistic youngsters are taught with vigor, compassion, and excellence. And then perhaps we can show the other 49 states how to do it!

References

Bartak, L. Educational Approaches. *Autism: A reappraisal of Concepts and Treatment*. M. Rutter and E. Schopler, Eds. New York: Plenum Press, 1978.

Krug, D. A.; Arick J. R.; and Almond, P. J. Autism Screening Instrument: Background and Development. *Autism: Diagnosis, Instruction, Management, and Research*. Austin: University of Texas Press, 1979.

Rutter, M. Developmental issues and prognosis. *Autism: A Reappraisal of Concepts and Treatment*. M. Rutter and E. Schopler, Eds. New York: Plenum Press, 1978.

Schopler, E. Changes of direction with psychotic children. *Child Personality and Psychopathology: Current Topics*. A. Dands, Ed. New York: John Wiley, Pub., 1974.

Sloan, J. L. and Schopler, E. Some thoughts about developing programs for autistic adolescents. *Journal of Pediatric Psychology*, 1977, 2, 187-190.

Sullivan, R. C. Autism: Current trends in services. *Autism*. Jamaica, N.Y.: Spectrum Publishing, 1976.

Wing, L. The handicaps of autistic children — a corporative study. *Journal of Child Psychology and Child Psychiatry*, 1969, 10, 1-23.

IOWA PERSPECTIVE

Vol. 5, No. 4 **May 1980**

Published by the Special Education Division, Department of Public Instruction, Grimes State Office Building, Des Moines, IA 50319. Carl R. Smith, editor.

STAFF

Drexel D. Lange, associate superintendent, Pupil Personnel Services Branch
J. Frank Vance, director, Special Education Division
Carol Bradley, chief, Instructional Services Section
Carl R. Smith, consultant, emotional disabilities and chronically disruptive
Marcia Olson, associate editor
Barbara Wilcots, graphics assistant
Joyce Short, compositor

Autism: A Legislative Issue

Proposed Legislation: H.F. 160

The Iowa legislature took up the issue of developing special programs for autistic pupils this past session when the House of Representatives passed House File 160 (see boxed item) on February 18, 1980. This bill would have required the Department of Public Instruction to differentiate autism from other areas of special education.

Arguments for and against this proposed legislation were presented to the Senate Subcommittee on Education. Instead of this proposed legislation, a joint Senate/House resolution was passed by the Senate on April 11, 1980 and by the House on April 26, 1980. The content of this resolution is provided below.

Section 1. Chapter two hundred eighty-one (281), Code 1979, is amended by adding the following new section:

NEW SECTION. AUTISTIC CHILDREN. The department of public instruction shall promulgate rules for the identification and development of special education programs appropriate for autistic children, as defined in section four hundred forty-four point twelve (444.12), subsection two (2), paragraph b, of the Code. The programs shall establish different weights, under the weighting plan established in section two hundred eighty-one point nine (281.9) of the Code as modified by the school budget review committee, for different manifestations of autism.

Sec. 2. This Act is effective January first following its enactment.

EXPLANATION

This bill requires the department of public instruction to promulgate rules for identifying and weighting autistic children and to develop programs for them.

The Final Joint Senate/House Resolution

WHEREAS, children who have been diagnosed as autistic or autistic-like represent a very low incidence population and present a variety of complex and unique educational needs requiring a variety of educational programs and services designed to meet those needs along a continuum of options that will provide appropriate programs from the mild to the very severely involved; and

WHEREAS, the State of Iowa is committed to the provision of appropriate educational programs and services for all of its handicapped children; and

WHEREAS, current state and federal statutes provide sufficient flexibility to implement the required programs and services to appropriately meet their needs; and

WHEREAS, there are concerns being expressed by professional educators and parents relative to the appropriateness of current programs and services currently implemented to meet the educational needs of such children; and

WHEREAS, there needs to be an intensification of effort by all agencies concerned with the education of handicapped children to properly identify autistic and autistic-like children, to determine their unique educational needs, and to implement appropriate programs and services to serve those needs, therefore,

BE IT RESOLVED, that the local education agencies and area educational agencies mobilize their resources to ensure that all autistic and autistic-like children have been properly identified; and

BE IT ALSO RESOLVED, that the Department of Public Instruction, with the cooperation of the LEAs and AEAs, implement a procedure to determine the specialized educational needs of this population; and

BE IT ALSO RESOLVED, the Department of Public Instruction promulgate additional administrative rules as necessary to provide appropriate educational programs and services for these children; and

BE IT ALSO RESOLVED, that the area education agencies and local education agencies in cooperation with the Department of Public Instruction implement the necessary educational programs and services to appropriately meet the needs of these children; and

BE IT FURTHER RESOLVED, that the State Board of Regents revise preservice preparation programs as necessary to include coursework emphasis adequate to prepare sufficient special education personnel to meet the educational needs of autistic and autistic-like children in Iowa.